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What is it like for autistic young people who feel distressed about their gender and bodies not matching?

This is summary of a research project. We wanted to learn about autistic young people who identify as transgender and have experienced distress linked to their gender and sex not matching. We interviewed young people and their parents separately. Quotes from young people and parents are written in bold and italics. In this document, you can find the important themes that came from the interviews. There are two main themes:

Section 1. Coping with distress

1. a) Understanding difficult feelings

1. b) Focus on reducing distress with support



Section 2. Working out who I am

2. a) The centrality of different identities and needs

2. b) Thinking about gender

Section 1. Coping with distress

1. a) Understanding difficult feelings

Young people felt unpleasant feelings which were difficult to understand and talk about. Almost all young people were very distressed by the mismatch between their gender identity and bodies, and puberty was very difficult.

“Puberty was really starting to take course, I really dipped which makes sense....it’s just my body was getting more and more masculine. My voice was getting deeper. I was getting taller. I was getting hairier and stuff and it just made me feel disgusted with myself”

Some young people noticed that sensory needs linked to autism interacted with their experiences of gender related distress.

“It’s probably enhanced it a bit ‘cause I get sensory overload quite easily. When all my sensory stuff is heightened I notice my body a lot more and I’m not able to take myself away from it and rationalise it”.

Young people told us that they experienced other mental health problems and difficulties too. They described how it could be difficult to express their feelings. Parents told us that they and their child spent lots of time trying to work out what was going on.

“most of his childhood, meltdowns have been really frequent...And it was with my thinking and reading and the help of our gender clinician and everyone at the clinic, helping to understand where that level of anxiety was coming from.”

1. b) Focus on reducing distress with support

Young people wanted to feel better and most of them wanted to make physical changes to their bodies through hormone treatments.

“...feels like I’m covered in like a thick coat of black paint that I can't get out of and when I’m sad like that, I feel trapped that I can't get out of it and there’s nothing I can do. With depression I can rewire my brain, I can't rewire my brain into not being trans, I have to wait for surgery which takes too long.”

Some participants did not want to change their bodies, including one non-binary person:

“I think medically and like physically there is nothing I can do about my gender because I can’t make my body more non-binary”

Sometimes parents were worried about their children having medical treatments and felt that their child should wait before accessing treatments.

“As painful as that is, I think [child]’s got to try and work out whether he can be happy without medical intervention, and I don’t mean ever, I can see that you don’t put a suicidal teenager on hormone blockers and hope that that’s going to make them happier”

At gender services, young people often found it difficult to communicate with clinicians.

“But sometimes - I’m not very good at the airy fairy sort of emotional talk they want to do. So they were not particularly receptive to me at first... they didn’t really – I don’t think they liked me very much.”

Young people described other difficulties going to gender and mental health services including:

- Busy waiting areas.
- Changing clinicians.
- Travel to clinics.
- Sensory overload in clinics.

Section 2. Working out who I am

2. a) The importance of different identities and needs

Young people felt different to other people their own age. Young people mostly talked about these differences as being linked to gender, but parents mostly thought these social differences were linked to autism.

Young Person: "when I got to secondary school I stood out quite a lot compared to other people. I was kind of singled out quite a lot so I had to try and fit in kind of, gender wise...I was kind of quiet and isolated and stuff so I would get picked on for like been quiet".

Parent: "I've always had an inkling that there was some kind of autism there. Getting it diagnosed is taking a long time but we've done it, but I think it was connected a lot of to the anxiety"

In contrast, most young people did not see autism as an important part of their identity:

"Well, I was diagnosed with autism and I just dealt with it. I didn't really care about it that much."

2. b) Thinking about gender

Young people and parents thought about gender in different ways. Young people sometimes spoke about how there was an interaction between autism thinking styles and thoughts about gender.

“I always thought it might be the autism affects me in the trans thing but it’s more that the trans thing has affected the autism if that makes sense. I used to think really black and white. Being trans has kind of made me stop doing that. I’ve had to move past it”

Parents were more likely to describe how autism influenced their child’s thoughts about gender, often talking about the influence of black and white thinking.

“Those conversations about fluidity have got shorter and shorter because it distresses [child]. That’s what I mean – it’s almost like he’s thinking, ‘You know. It’s black or white. It’s on or off. I identify here.’”

Parents spoke about how black and white thinking made their child feel more frustrated about accessing gender clinics.

“With autism, it’s black or white. ‘I’m doing this and I’m doing it now’. It’s like, no, you need to slow down a bit. You can’t always rationalise with him about it. Well, ‘I’ve decided, and I’m getting it sorted’.”

Some young people spoke about how being autistic helped them to better understand gender.

“...it’s not very complicated to me so I’m able to distinguish sex and gender and it’s not like I look at it and get confused”

In contrast, some parents wondered if their child’s differences in social understanding impacted their ability to understand gender.

“I do wonder looking back – beauty of hindsight – how much the autism impacted on his ability to understand his gender, A. in relation to himself and B. in relation to everybody else.”